Report from the

Committee on Health Care and Income Support

TO THE PRESIDENTIAL TASK FORCE ON EMPLOYMENT OF ADULTS WITH DISABILITIES

Chair:

Donna Shalala, Secretary
Department of Health and Human Services

Vice Chairs:

Kenneth Apfel, Commissioner
Social Security Administration

Nancy-Ann DeParle, Administrator
Health Care Financing Administration
Department of Health and Human Services

THE SECRETARY OF HEALTH AND HUMAN SERVICES
WASHINGTON, D.C. 20201

The Honorable Alexis Herman
Chair, Presidential Task Force on
the Employment of Adults with Disabilities
Tony Coelho, Vice Chair
U.S. Department of Labor
200 Constitution Avenue, N.W.
Room S-2220
Washington, DC 20210

Dear Secretary Herman and Vice-Chair Coelho:

On behalf of Nancy-Ann Min DeParle, Administrator of the Health Care Financing Administration, and Kenneth Apfel, Commissioner of the Social Security Administration, I am pleased to present two Work Group reports from the Presidential Task Force's Committee on Health Care and Income Support. In the two enclosed reports, the Committee's two work groups identify a number of policy, budgetary, and legislative recommendations where health care and income support can be improved to support employment of adults with disabilities.

The first report contains the recommendations of the Work Group on Health Care. Recommendations include increasing access to health care benefits and programs, increasing state participation in health and income support programs, obtaining consumer and state input on how to improve existing work incentive programs, the passage of legislation that supports people with disabilities who want to work, and additional research and demonstration activities to support and promote employment opportunities for adults with disabilities.

The second report contains the recommendations of the Work Group on Income Support. Recommendations include options for updating the "Substantial Gainful Activity" (SGA) dollar amount on a regular and periodic basis, a proposal to consider an increase in the Trial Work Period services dollar amount and having it keep pace with increases in general wages, and a recommendation to adjust the earned income exclusion in order to maintain it at an amount that keeps up with growth in the Social Security benefit rates.

We look forward to reviewing the Task Force's recommendations to the President in the annual report. As our Work Group reports highlight, we have many barriers and challenges to address as we think about ways to support the employment of adults with disabilities. We are eager to redouble our interagency efforts and are confident that, with the passage of the Work Incentives Improvement Act and the implementation of our Work Group recommendations, we will continue in the right direction.

Sincerely,

Donna E. Shalala

Health Care and Income Support Committee

Mission

The mission and focus of the Presidential Task Force on Employment of Adults with Disabilities' *Health Care and Income Support Committee* is to determine what actions Federal agencies can take to improve employment outcomes of people with disabilities by (1) facilitating access to appropriate and affordable health benefits and services, including long-term care services and supports, and (2) developing strategies for reducing and avoiding reliance on income support programs.

To carry out the tasks needed to fulfill this mission, the Committee divided into two work groups, the *Health Care Work Group* and the *Income Support Work Group.* After the initial Committee meeting, each work group met separately to discuss current activities and areas of potential collaboration, and to develop an action plan. Each has prepared a report detailing their recommendations.

Health Care Work Group Report

Background

One of the most critical issues that the Task Force is addressing is the need for health care and home and community-based services and supports for people with disabilities who want to work. Without access to these services, many people with disabilities are unable to live in the community at all, much less participate in the work force. Concerns about health and the fear of losing health care coverage are major issues for many people with disabilities who want to work.

The Medicare and Medicaid programs are primary payers of services provided to persons with disabilities. While they were never intended to support the employment of people with disabilities, there is increased attention being focused on how to use the benefits provided by the two programs to return people to the work force. The services under these programs can be linked with other State or Federal programs, such as vocational rehabilitation services funded through the Rehabilitation Act, to provide a more comprehensive set of supports enabling people with disabilities to enter and remain in the work force.

The Medicaid Program — The Federal-State Medicaid program is a funding source for valuable acute care services, as well as long-term care for people with disabilities. The original intent of the Medicaid program was to provide health care to low income individuals who were out of the labor force. Many people with disabilities now can and want to work; some require the types of services provided by Medicaid. Thus analysts and policy-makers are examining ways to make Medicaid more accessible and responsive to people with disabilities who work.

Under Medicaid, each participating State must provide certain mandatory services to entitled groups and may elect to offer select optional services:

- Mandatory services include hospital and physician services, home health, nursing facility care, and early and periodic screening, diagnosis and treatment.
- Medical equipment, supplies and appliances which are part of home health services, a critical service for many people with disabilities, are mandatory for certain eligibility groups.

A number of optional services are available under the Medicaid program as State plan options or through home and community-based waivers which provide support to people with disabilities who wish to return to the work force or remain in the work force;

- Optional State plan services include personal care services (also called personal assistance services or attendant care) which can be provided outside the home to a person with a disability requiring assistance with "activities of daily living" and/or "instrumental activities of daily living" in the workplace.
- Home and community-based waiver services may include pre-vocational and supported employment services as a component of habilitation, personal care services, medical equipment and supplies, assistive technology, and transportation services.

The Medicare Program — Medicare is a Federal program that offers primarily acute care benefits and focuses on "medical necessity." The covered benefits were not designed for people returning to work, or more generally people with disabilities, but emphasize recovery after acute illnesses and are less comprehensive than the Medicaid program. For example, Medicare does not cover prescription drugs and has only a limited home health benefit. While most of Medicare's expenditures are for acute services, such as physicians' services and hospital care, Medicare provides some essential services for people with disabilities, such as diagnostic services, rehabilitation hospital services, and physicians' services.

Issues and Barriers — Since some people with disabilities have higher health care expenditures, more doctor visits, and more hospital stays each year, private insurance for people with disabilities can be very costly. Most people with disabilities who are enrolled in Medicare or Medicaid do not work or earn only limited incomes; this enables them to stay enrolled in Medicare or Medicaid and retain income support benefits.

National Social Security data indicates that approximately 8 million people with severe disabilities are currently unemployed or underemployed and receive cash benefits under the Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI) programs.[1] The unemployment rate among people with disabilities is extremely high, with some estimates as high as 75 percent. The most frequently reported barrier to returning to or entering the work force is the loss of health care benefits or the fear of losing health care benefits. SSDI and SSI, the income support programs that trigger eligibility for Medicare and Medicaid, each have work incentives that enable beneficiaries to participate in the work force and retain health coverage; however, few beneficiaries find these work incentives viable.

The majority of people with disabilities who are employed are covered under private health insurance policies; however, many of these plans do not cover services needed by people with disabilities who are employed, and often what is offered is prohibitively expensive.

These types of information and data raise a number of important questions that the Committee's *Health Care Work Group* has been examining and beginning to address:

- How can government programs do more to encourage people with disabilities to become gainfully employed?
- Are there regulatory barriers within existing programs that serve as disincentives to seeking employment?
- How can the Federal and State governments work together to encourage greater access to personal assistance services and other home and community-based services needed by people with disabilities who work?
- What more can the government do to link service systems that address the education, training, employment and health care systems with the ultimate aim of getting more people into good jobs, earning a living wage?

[1]As of June 1999, the Social Security Administration reported that 2.65 million people with disabilities received SSI, 4.50 million received SSDI, and 1.06 million received both SSI and SSDI.

Efforts Already Underway

A. Interagency Efforts

1. **State Partnership Initiative Grants** — In 1998, the Social Security Administration (SSA), in partnership with the Department of Health and Human Services (HHS), Center for Mental Health Services (CMHS), the Rehabilitation Services Administration (RSA) and the Department of Labor, awarded cooperative agreements to 12 States under the State Partnership Initiative: California, Illinois, Iowa, Minnesota, New Hampshire, New Mexico, New York, North Carolina, Ohio, Oklahoma, Vermont, and Wisconsin.

   The initiative, funded at approximately $35 million over 5 years, is designed to help States develop innovative and integrated Statewide programs of services and supports for their residents with disabilities that will:

   - Increase job opportunities;
   - Decrease dependence on public benefits, including SSI and SSDI; and
   - Improve continued access to health insurance for those who start or return to work.

   SSA awarded an evaluation contract to Virginia Commonwealth University to provide technical assistance to the States and to monitor and collect data on the State projects. All of the projects are underway and most are enrolling participants and beginning to collect data. RSA is working closely with SSA on the evaluation component of the project and has included six similar State/local community employment projects in the data collection effort.

2. **Treatment of Affective Disorders Project** — The Social Security Administration, with advice and consultation from the Department of Health and Human Services' Center for Mental Health Services, has committed to fund a demonstration to study the effectiveness of treatment on employment and wellness. The prognosis for controlling the episodes of mania and depression is good with psycho-pharmacologic therapy and/or psychotherapy. Research suggests that as many as 60 to 80 percent of affective disorder cases can be effectively controlled. The extent to which these encouraging statistics relate to SSA beneficiaries with disabilities is unknown. This demonstration will attempt to answer this question by offering beneficiaries, through their treating sources, free treatment for their affective disorders. After agreeing to satisfy specific conditions, the treating sources/beneficiaries will be able to select from a variety of treatment modalities. Treatment will be continued for an extended period, if the prognosis for improvement continues. Access to return to work services will also be provided to assist beneficiaries to move from the rolls to economic independence. The demonstration is scheduled to run for five years.

3. **Preparing for Implementation of Work Incentives Improvement Act (WIIA)** — SSA and the Health Care Financing Administration (HCFA) are actively working toward implementation of the Ticket to Work and Work Incentives Improvement Act of 1999 (TWWIIA). SSA has developed language for notices with HCFA input pertaining to the section of the Act that applies to continuation of Medicare coverage and has entered into an agreement with HCFA staff for expedited notice clearance upon passage of the TWWIIA. Since portions of the TWWIIA are effective on the first day of the month following enactment, preliminary action is necessary for effective implementation.

4. **Internet Information Sources** — SSA's Office of Employment Support Programs website **(www.ssa.gov/work)** has a link to HCFA's site and has recently added a section entitled "Health Care for People with Disabilities."

B. Departmental Efforts

1. **Research Agenda** — HHS has a solid research agenda which is underway to review the evidence that supports the proposition that people do not seek work because they fear losing health coverage. While there are few empirical studies to date, it is clear from the data we have that

health care access is an important factor in the decision to seek work.

Currently, a study is underway to look at labor force participation and earnings levels of people with disabilities in Tennessee and Oregon before and after substantial Medicaid expansions in those states. In addition, HHS is analyzing data from the National Health Interview Survey on people with disabilities, the first comprehensive survey of Americans with disabilities. This survey will provide information and data needed to gain a better understanding about earnings, barriers, accommodations and health care spending and utilization. Lastly, CMHS is conducting the Employment Intervention Demonstration Program which is a five-year demonstration being carried out in eights sites to identify and evaluate the types of supports most effective for helping people with psychiatric disabilities find and maintain employment. The effects of employment on the use of mental health services and public entitlements is being measured.

2. **Patient's Bill of Rights Legislative Effort —** There are few populations in this country who will benefit more than people with disabilities from the passage of the Administration's Patient's Bill of Rights. Ensuring continuity of care, access to specialists, and appeal rights, are absolutely critical to ensuring a greater level of confidence in the health care system among people with disabilities.

3. **Implementing Section 4733 of the Balanced Budget Act of 1997 (BBA) —** HHS continues to work with the States to implement Section 4733 of the Balanced Budget Act, which permits States to allow working individuals with disabilities with incomes up to 250 percent of the Federal poverty level to buy into Medicaid. The Secretary sent a letter to all the governors informing them of the BBA option providing Medicaid eligibility to people who work. Similarly, the Health Care Financing Administration (HCFA) sent a letter to all State Medicaid directors to encourage them to use the new eligibility option. At the time this report was prepared, only six States had added this option to their Medicaid plan. HHS has worked with Congress to identify reasons why States are slow to take advantage of this option, and to address State concerns through legislative modifications in the Ticket to Work and Work Incentive Improvement Act of 1999 (TWWIIA). HHS believes this provision, and the recently passed TWWIIA, are both important links to achieving the goal of helping people who want to work by providing affordable health care.

4. **Personal Care Services —** HHS recognizes that the availability of personal care services is also a critical element in enabling people with disabilities to work. Personal care services are an optional State plan service under Medicaid, and at last count, 28 States offered this optional service to adults with disabilities. In September 1997, HHS published a regulation on personal care services under Medicaid providing more flexibility to States and encouraging the expansion of this option. This rule gives States the option to expand the availability of personal care services by allowing services to be provided outside the home.

5. **Improving Scientific Knowledge —** Within the National Institutes of Health, the National Center for Medical Rehabilitation Research is actively working to develop scientific knowledge needed to promote the health, productivity, independence, and quality of life for people with disabilities. They have accomplished this by supporting research to enhance the functional abilities of persons with various disabilities.

Recommendations

The *Health Care Work Group* identified the following issues related to the improvement of employment outcomes for people with disabilities and made preliminary recommendations for addressing these issues and barriers.

Issue: *Congress changed the Medicaid eligibility rules for working individuals with disabilities when it passed section 4733 of the Balanced Budget Act of 1997, allowing States to offer a buy-in to Medicaid to individuals whose income is below*

250 percent of the Federal poverty level. To date, six States have implemented the Balanced Budget Act provisions.

Recommendation: More States need to be encouraged to implement the Balanced Budget Act Medicaid buy-in provisions:

- HCFA will continue to provide technical assistance and advice to States interested in implementing the current Medicaid buy-in provision.
- HCFA, the Social Security Administration, and the Rehabilitation Services Administration will work together to interest States already undertaking work incentives demonstrations sponsored by these agencies to take up the BBA Medicaid buy-in. HCFA will build on this experience to ensure the effective implementation of the Work Incentives Improvement Act once it becomes law.
- HCFA will identify key individuals from States that have successfully developed BBA State plan options and other work incentive programs and encourage those individuals to provide technical assistance to other States. The technical assistance provided by HCFA and its State partners will be mindful of the cultural preferences of the beneficiaries in different regions of the country.
- The Task Force will work with HCFA to investigate issues related to State participation in the buy-in option.

Issue: *Current limitations in work incentives programs related to income limits and continuation of benefits are addressed in the Ticket to Work and Work Incentives Improvement Act of 1999 (TWWIIA). These limitations include an income ceiling for beneficiaries eligible for Medicaid and the termination of Medicare benefits following an extended period of eligibility. Implementation of TWWIIA will challenge the Department of Health and Human Services to ensure that the health care provisions expanding eligibility criteria and extending benefits are effective. Cooperation in implementation across agencies will increase the likelihood of success.*

Recommendation: The Department of Health and Human Services will develop a comprehensive blueprint of implementation activities to be submitted to the Presidential Task Force on Employment of Adults with Disabilities for review after the Ticket to Work and Work Incentives Improvement Act is signed by President Clinton.

The Administration participated in developing and fully supported the Ticket to Work and Work Incentives Improvement Act of 1999, passed by both the U.S. Senate and House of Representatives in November 1999. The Act includes the following provisions related to health care for people with disabilities who start or return to work:

- Health insurance through Medicaid by providing States with an option to offer a buy-in to people with disabilities by lifting Federal eligibility limits on assets and earned and unearned income.
- An option for States to continue coverage (on a buy-in basis) for working individuals with disabilities whose medical conditions remain, but who would otherwise lose eligibility due to medical improvement.
- Health insurance through Medicare by extending lifetime coverage under Medicare Part A to any individual who loses Social Security due to their ability to work and earn a living during a specified time period following enactment of the legislation.
- Infrastructure grants for States that take advantage of the Medicaid buy-in for working individuals with disabilities and offer personal assistance services (PAS). These grants would be used to assist in developing infrastructures that facilitate return to work and for outreach campaigns to connect individuals with services.
- $250 million for a five-year demonstration program would allow participating States to provide Medicaid-equivalent services to individuals with health conditions that have not yet rendered them blind or disabled, but that can be expected to cause the level of disability required to qualify for SSI/SSDI.

The implementation plan will include technical assistance efforts, research and evaluation projects, data linking activities, outreach and enrollment activities, and issuance of State guidance on both the new legislation and existing work incentives programs. A goal of each of these activities will be to ensure that all materials developed are culturally sensitive and respectful of the preferences of our beneficiaries.

The plan will coordinate with the efforts of other Federal agencies such as the Department of Education, the Department of Labor (DOL), and the Social Security Administration. HCFA will make concerted efforts — in consultation with the States, the disability community and other Federal agencies — to ensure the effective and widespread implementation of the Medicaid buy-in and infrastructure development grant provisions of TWWIIA once it is enacted into law. In particular, HCFA will: (1) begin to provide information on the major health care access provisions to States and disability groups, e.g., through correspondences with the governors, State Medicaid Directors and via the Web; (2) provide technical assistance and support to States wishing to take up the Medicaid buy-in and demonstration provisions of the new law; and (3) expeditiously award infrastructure development grants to States which participate in the Medicaid buy-in.

Issue: *Both the SSDI and SSI programs offer work incentives that enable beneficiaries to continue receiving income supports and health care coverage after returning to work. Participation rates in these work incentives are very low and should be increased though outreach, public education, and technical assistance activities. In addition, the Federal government should engage in longer term planning to develop a single set of messages from all agencies, that can be clearly understood by all constituencies.*

Recommendation: HHS, DOL, SSA and RSA will form an interagency workgroup to develop a consumer outreach campaign to raise awareness around work incentives and facilitate individual participation in work incentive programs (such as 1619 and the Program for Achieving Self-Support or "PASS"). This work group will coordinate State outreach and consumer education efforts, examine knowledge and attitudinal barriers to consumer participation in work incentive programs, and make recommendations on current and future programmatic and budget efforts related to consumer education of work incentive programs.

In the short term, HHS, DOL, SSA, and RSA will work together to develop more user-friendly resources and consumer resource guides synthesizing existing health and income related work incentive programs, benefits and demonstrations at the Federal and State levels. These resource guides will provide technical assistance to people with disabilities and the disability community about the health and income-related resources currently available which will enable individuals to succeed in the work force.

In the next 12 months, the workgroup will identify joint technical assistance, outreach, education and coordination activities they can undertake to promote the increased use of existing work incentives, particularly by young people with disabilities ages 16 to 25. In order to ensure that a broad audience is exposed to information about work incentives, HCFA will participate along with other Federal partners in SSA's targeted public education events for consumers, advocates, State officials, providers, and any other interested parties over the next fiscal year. Topics for such events will include: (1) SSA - Field Office Employment Initiatives; (2) Customer Service Improvements; (3) Health Care Initiatives and Options; (4) TWWIIA Update; (5) Best practices from the States; and (6) Other local issues.

Finally, SSA will develop and begin implementation of a customer service improvement plan in FY 2000 which will focus on providing more timely and accurate information at the Field Office level to SSI and SSDI beneficiaries who pursue employment or return-to-work.

Issue: *Medicaid, as virtually the only public payor of long-term supports, offers States a great deal of flexibility in structuring and delivering consumer responsive long-term support and personal assistance services programs. States need information and incentives to maximize this flexibility.*

Recommendation: HHS will promote and expand its technical assistance to States – supporting States in developing and improving consumer responsive home and community based services systems. Such systems are critical for many people with disabilities who work. HHS will ensure that the employment aspect of this work is highlighted. As the focal point for these activities in FY 2000, the agency is developing a resource center for States, advocacy groups, and consumers to use in order to promote home and community-based alternatives in their States. In addition, HHS will be completing its "Medicaid Primer," a synthesis of information that will explain in clear language what flexibilities States have under Medicaid to deliver home and community based supports and provide examples of what a number of States have done in this regard. HHS will ensure that people involved in employment services and supports have access to the "Primer," so there is an accurate, common understanding of Medicaid provisions.

Issue: *People with disabilities have a number of concerns related to the design and delivery of health care services. Issues include access to facilities, access to specialists, quality of care, and appeals. The issues become even more prominent for people with disabilities who work. Medicare and Medicaid should be studied and improved to assure that these concerns are addressed, both in managed care and fee-for-service contexts.*

Recommendation: HHS has undertaken a research agenda focusing on health care and people with disabilities. Projects include qualitative and quantitative analyses of Medicaid managed care, care coordination and single point of access. A critical factor in providing quality health care to Medicaid beneficiaries is service coordination both in managed care and fee for service environments. HCFA will research care coordination for Medicaid services in both fee-for-service and managed care delivery systems, in order to share with all State Medicaid agencies a composite summary of care coordination models used by States that enhance access to health care services that may be critical for employment by beneficiaries with disabilities. In addition, HCFA will develop new policies and initiatives to reduce identified barriers to service coordination for working people with disabilities.

In addition, the Administration has strongly supported and will continue to support legislation to establish a Patient's Bill of Rights. This proposal would have a profound effect on people with disabilities who participate in managed care, and would forbid exclusions of pre-existing medical conditions and discrimination against people with mental illnesses.

Issue: *The absence of prescription drug coverage, while a problem for most Medicare beneficiaries, becomes a highly critical issue for people with disabilities, particularly those with mental illness. Work is not possible for many people with psychiatric disabilities when prohibitive expense prevents access to specific drug classes.*

Recommendation: The President recently proposed sweeping Medicare reforms that will improve and preserve the program. One of the most crucial changes for the disability community, particularly individuals with mental illness, is the proposed addition of a prescription drug benefit. Currently, Medicaid is available to pay for drugs for some of these individuals, if their income is within certain limits. Those who do not have Medicaid, or other means of paying for prescription drugs, frequently go without, unable to pay out of pocket for medication. Without medication, people with mental illnesses may have more difficulty controlling symptoms, potentially reducing their chances of successfully maintaining employment. The Administration will continue to promote its Medicare reform proposal and highlight the important need for a prescription drug benefit in Medicare.

Issue: *People with disabilities, especially those who work and purchase personal assistance services out of pocket, experience proportionately higher expenses in order to work. Such individuals, and their families, should be afforded some financial relief.*

Recommendation: The President has proposed a package of long-term support reforms, many of which will benefit individuals with disabilities who work. One element of this package is an unprece-

dented tax credit for people with disabilities and their caregivers. This proposal will support and recognize the family, which is still the predominant care delivery system for people with disabilities, by providing needed financial support to about 2 million Americans including employed individuals with disabilities.

Issue: *A number of activities are already underway to support youth with disabilities as they transition into adulthood, but these activities are not currently coordinated across departments.*

Recommendation: The Administration (led by HHS, the Department of Education, and SSA) will form an interdepartmental workgroup to develop recommendations on how Federal agencies can collectively provide more effectively targeted services to youth as they transition to adulthood and the work force. Specifically, the needs of youth transitioning from pediatric to adult health care, secondary to post-secondary education, and school to work will be addressed.

Issue: *There are a number of research, demonstration and evaluation projects that could inform the planning and development of services and benefits needed by people with disabilities who work.*

Recommendation: HHS and SSA will develop a coordinated research work group that will develop an interagency research agenda within the next six months and present it to the Task Force.

Issue: *People with disabilities are in the unique position of being able to identify issues and concerns with the current income support and health programs. They see the problems first hand and they frequently have ideas for workable solutions. There is no organized forum for HCFA and SSA to hear from consumers.*

Recommendation: Consumers who have attempted to return-to-work view SSA programs as punitive and express frustrations regarding complex regulations regarding eligibility and application for Social Security and Medicaid and Medicare programs. They complain of discrimination against people with psychiatric disabilities and of poor service, inaccurate information and archaic rules. SSA and HCFA should consider developing and implementing a plan to actively seek out consumer input, and have a regular mechanism for assessing the impact of their regulations on the lives of people with disabilities.

Issue: *Chronic diseases/health conditions interfere with the employment of people with disabilities and the general adult population. Advancements in genetic technology will offer the opportunity to screen for many common chronic diseases, to offer early intervention, and early health promotion activities aimed at life-style changes in order to help people remain healthy.*

Recommendation: HHS should provide discretionary grant support to the States through Title V of the Social Security Act to develop strategic plans to expand genetic testing, counseling, and treatment services to include adults.

As the sequencing of the human genome is completed, the opportunity to transition genetic knowledge and technology into health practice will increase. This will provide health systems with the ability to better understand genetic contributions that promote better health programs for adults which would provide testing, counseling, and treatment aimed at keeping the adult population healthy and able to work.

Income Support Work Group Report

Background

The *Income Support Work Group* focused on the issue of providing income supports that are structured so as to create financial incentives to return to work while offering adequate support for those unable to work. This is a challenge for all income support programs, which typically eliminate or reduce benefits substantially as recipients receive other income. Faced with such a tax, as well as the potential loss of health insurance, beneficiaries who

might be able to work conclude, with good reason, that they are better off not working.

The two major cash support programs for people with disabilities are administered by the Social Security Administration. The Disability Insurance Program (SSDI), authorized under Title II of the Social Security Act, provides income to persons who become disabled after working in covered employment and paying Social Security taxes. It is designed to replace a portion of their lost income if they are unable to earn a specified income — currently $700 a month. The Supplemental Security Income Program (SSI), established under Title XVI of the Act, is a social assistance program that pays monthly cash benefits to individuals who are blind or disabled, and who have limited income and resources. While eligibility for the programs is based on beneficiaries' inability to engage in substantial work activities, both programs nonetheless have provisions to facilitate and provide incentives for work.

SSDI beneficiaries who work receives the benefit of a nine-month Trial Work Period, during which their benefit amounts are not affected. Then, the work is examined by SSA to determine if it is "Substantial Gainful Activity." If so, then after a three-month transition period, the SSDI benefit is terminated. There is no provision for a partial benefit under SSDI. Medicare coverage can continue for some period even after an individual's cash benefits stop, and there is a provision for a return to benefit status if the work attempt is not fully successful.

An SSI beneficiary who works does not have a Trial Work Period. Instead, the first $65 of monthly earnings are excluded, and then the monthly cash benefit is reduced by $1 for every $2 of monthly earnings. As wages increase, the cash benefit decreases. If the wages are high enough to reduce the benefit to zero, then Medicaid eligibility can continue as long as the person needs Medicaid to continue working and cannot afford to purchase private health insurance. These work incentive provisions (for extending partial cash benefits or Medicaid) are called Section 1619A and B provisions.

Additionally, beneficiaries can participate in the Plan for Achieving Self-Support, or PASS, program. In a PASS, the beneficiary identifies:

- A specific goal in employment or self-employment;
- The steps he or she must take to reach this goal;
- The expenses that these steps will involve; and
- The funds to be used for these expenses.

Expenses can be approved for such things as education, training, assistive technology, childcare, transportation, business costs, and supported-employment if they are necessary for achieving the goal. SSA determines SSI eligibility and payment amount without counting the funds to be used for approved expenses. The resulting SSI benefits then replace part or all of these funds.

Interagency Efforts Already Underway

A. State Partnership Initiative Grants — The State Partnership Initiative. Grants, which involve both health care and income support innovations, are described in the *Health Care Work Group* report, above.

B. Treatment of Affective Disorders Project — This project, which also involves both health care and income support policies and benefits, is described in the *Health Care Work Group* report, above.

C. Internet Information Sources — SSA's Office of Employment Support Programs Web site **(www.ssa.gov/work)** has a link to HCFA's site and has recently added a section entitled "Health Care for People with Disabilities."

Recommendations

The *Income Support Work Group* has identified the following issues related to the improvement of employment outcomes for people with disabilities and made preliminary recommendations for addressing these issues and barriers.

Issue – Substantial Gainful Activity: *On April 15, 1999, SSA issued final rules to increase the monthly substantial gainful activity (SGA) amount from $500 to $700, effective July 1, 1999.[2] The SGA amount indicates whether an individual is able to perform a substantial level of work based on the amount of pay that he or she earns. Without that increase, the SGA would have fallen farther behind the growth in wages and therefore would not be a good indicator of ability to work. However, there is no regular process for updating the SGA amount.*

Recommendation: To ensure that the SGA keeps up with wage growth in the future, the *Income Support Work Group* recommends that the Social Security Administration consider fiscally sound ways to update the SGA amount on a regular periodic basis.

The Social Security Act defines disability as the "inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment…".[3] The statute does not define SGA, but rather requires the Commissioner to establish by regulation the criteria for determining when services performed or earnings derived from services demonstrates a non-blind individual's ability to engage in SGA. Generally, one of the measures the Commissioner uses in determining whether an applicant or beneficiary is engaging in SGA is the amount of pay that the individual has actually earned.

In evaluating initial claims for disability, a determination is made as to whether the applicant for Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI) disability benefits is engaging in SGA. Applicants are determined "not disabled" if they are working and performing above the SGA amount regardless of their medical condition. In addition, after an individual becomes entitled to SSDI benefits, the SGA amount is used as a measure in determining ongoing entitlement to SSDI benefits; it is not used as a measure for continuing eligibility for SSI benefits.[4]

Through periodic adjustments, the SGA amount kept nearly even with average wage growth until 1980. As a result of reliance on ad hoc increases, the SGA amount in recent years has fallen considerably behind average wage growth for two long periods of time. The SGA amount was not raised again until 1990, when it was increased from $300 to $500. The most recent increase became effective on July 1, 1999, when it was increased from $500 to $700, the approximate level that it would have attained if it had increased at the same rate as average wages had grown since 1990.

A regular and predictable mechanism to increase SGA would ensure (1) a consistent relationship between the SGA amount and future wage growth; and (2) that the work component of the definition of disability over time keeps up with average wage growth.

Issue – Trial Work Period: *The ultimate goal of work incentives is to help beneficiaries become self-sufficient. Work incentives in current Social Security law are based on the premise that disabled beneficiaries are more likely to work if their wages do not immediately jeopardize their receipt of cash and medical benefits, and if they are better off financially by working than by not working. The Social Security Disability Insurance (SSDI) program provides an important opportunity and incentive to return to work in the form of a trial work period. Beneficiaries can have a Trial Work Period (TWP) consisting of nine months, not necessarily consecutive, during which individuals can earn any amount without affecting their benefits.*

[2]The SGA amount for individuals who are not blind is prescribed by regulation. Unless specifically noted, this paper refers to the SGA amount for the "non-blind." The SGA amount for the blind is established by statute and is adjusted annually in accordance with increases in the Social Security National Average Wage Index. The SGA amount for individuals who are blind is currently $1,110 per month.

[3]See § 223(d)(1)(A) of the Social Security Act.

[4]Although the SGA amount is not used as a measure for continuing eligibility for SSI benefits, the amount is used as a determinate for entry into the 1619(a) program. Section 1619(a) of the Social Security Act allows SSI recipients to receive cash benefits even when their earnings exceed the substantial gainful activity amount. SSI monthly payments are reduced $1 for every $2 for earnings over the applicable income exclusions.

This affords them a relatively risk free way to test their ability to return to work. The Commissioner of Social Security establishes the monthly earnings level that constitutes a trial work month — currently $200. That amount has not been increased since 1990. Because of wage growth since that time, the actual amount of work represented by the $200 amount has declined.

Recommendation: The *Income Support Work Group* recommends that Social Security consider whether an increase in the TWP services amount is warranted and should consider how it should keep pace with future increases in wages.

The trial work period originated in the 1956 law which established the SSDI cash benefits program. A month is counted toward the TWP when services are rendered in that month. During the 1960s, there was no way to avoid including insignificant work as a month of services in the trial work period. Experience showed that beneficiaries frequently used several months of a TWP while making intermittent and insignificant efforts to work. When these individuals finally reached a productive earnings level, the TWP was exhausted, although they had not demonstrated the capacity to sustain competitive employment on a regular basis. Therefore, in 1968, the Agency approved a policy that work activity for earnings not exceeding $50 a month would be excluded from the TWP on the basis that the work involved may be viewed as "insignificant work which does not in any real sense constitute a trial work or rehabilitation effort." Social Security increased the level to $75 in 1979, and $200 in 1990. Although average wage growth and the dollar figure that represents SGA have risen since 1990, the $200 amount has not changed.

Currently, if beneficiaries earn as little as $201 in a month, they have completed one successful trial work month. The current $200 monthly level represents only about 39 hours of work at minimum wage. Because this services amount represents approximately one week of full-time work, beneficiaries can exhaust their months of trial work without having demonstrated the ability to sustain meaningful work activity.

Increasing the TWP services amount would offer three advantages. First, beneficiaries might be more willing to start working since the risk to beneficiaries of working would be substantially reduced. Beneficiaries could experiment with various employment opportunities and workloads before their trial work period expired. Secondly, beneficiaries would be able to engage in part-time work without accumulating trial work months. This would be especially helpful to beneficiaries who may desire to work, but can only do so intermittently or for a short duration. Finally, a higher TWP service amount would make the TWP a better test of ability to engage in substantial gainful activity. Therefore, workers who completed the trial work period would be more likely to succeed in work after the trial work period ends.

Issue – SSI Earned Income Exclusion: *Supplemental Security Income (SSI) is a means tested program, but beneficiaries are able to have nominal earnings before experiencing any reduction in benefit amounts. Allowing such earnings not only increases overall income security, but also provides an incentive to work. Currently, beneficiaries are allowed an earned income exclusion of $65 per month without loss of benefits.*

The portion of an SSI beneficiary's wages excluded for purposes of calculating benefits equals the amount of the earned income exclusion (EIE) plus half of any wages exceeding the EIE. The EIE has been the same amount since it was first established in 1972.

Although the SSI Federal benefit rate and Social Security benefits are indexed annually for inflation, the earned income exclusion ($65) has not been adjusted since the SSI program was enacted in 1972. For example, the earned index exclusion would be $289 if it had been indexed to average wage growth and $255 if it had been indexed to prices. Therefore, SSI beneficiaries with non-SSI income do not receive full indexing of their benefits, and work effort is less rewarded than it was previously.

Recommendation: The *Income Support Work Group* recommends that the Social Security Administration consider adjusting the earned income

exclusion in order to maintain an amount that keeps up with the growth in benefit rates.

This policy change would help low-wage workers with disabilities. An increase in the earned income exclusion, for example, to $250, would increase benefits for over 200,000 SSI beneficiaries and would increase the total income of beneficiaries with average wages to at least the Federal poverty threshold. Additionally, it would encourage work effort by increasing the total income available to beneficiaries before losing all cash benefits.

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